# PERSPECTIVE S in genetic counseling

Volume 23 Number 1 Spring 2001

national society of genetic counselors, inc.



the leading voice, authority and advocate for the genetic counseling profession

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NSGC acknowledges Women's Health Care Services of Wichita, Kansas, for a grant to support this newsletter.



Women's Health Care Services, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director. 800-882-0488.

# INTERNET AGE FOR NSGC: CULTURE SHIFT OR CULTURE SHOCK

Janice Berliner, MS & Beth Billings, MS

#### BACKGROUND

urrently, NSGC's Board of Directors is reviewing our finances and is considering a five-year financial forecast. We have many goals that will support our strategic plan and further our vision and mission. In thinking about how to save money, the idea has been generated to introduce some of our hard copy publications, such as our Annual Education Conference brochure, our Membership Directory and even this newsletter into the Members' Corner area of our website.

### **OUR COMMITMENT**

Hard copies would be available to any members who are not online or by request. We are considering a small charge for members who have online access, but request hard copies.

### THE PROS

- Tremendous savings in printing and mailing costs, funds could be diverted for major "big ticket" items such as marketing the profession, expansion of our executive office and studies of reimbursement issues, to name only a few.
- Saved paper would be friendly to our environment.
- Ready access and update-able online directory information makes our membership more accessible. NOTE: For security reasons, this online database would *not* tie into our

Executive Office database, although changes could be electronically sent to our office for updating.

• Index, archive and search capabilities could be introduced for *Perspectives*.

#### THE CONS

- Security. Any website is vulnerable to intrusion, even with password protection.
- Although members will be asked to keep their unique passwords private, there is no guarantee.
- Public access could lead to inappropriate use of the directory information, e.g. advertising to members.

### YOUR OPINION COUNTS!

Inside this issue you will find a yellow postcard asking for your opinion. Please respond by the April 18 deadline. Your opinion is vital to enable us to have a measured, comprehensive discussion at our April 27-29 Board meeting. �

In Your Mailbox
Earlier this month, each
NSGC member was sent a
membership card which
included a Unique ID# and
information about how to enter our
new website's password protected
area. Please be sure to keep the card
and your number in a safely
guarded place. ❖

# PRESIDENT'S BEAT

The following represents excerpts of formal oral testimony given by NSGC's President, Vivian Weinblatt, at the February 16 meeting of the Secretary's Advisory Committee on Genetic Testing (SACGT). This testimony has been entered into the public record.

I am pleased to speak on behalf of the NSGC, the leading voice, authority and advocate of the genetic counseling profession.

We commend the SACGT on its accomplishments to date, including its recommendations for oversight of genetic testing, development of a test classification system and creation of an information template to educate health professionals regarding the unique nature of genetic tests.

I will address three aspects of genetic testing that require attention as your working groups continue their assigned tasks: informed consent, result reporting and access to care.

### INFORMED CONSENT

The process of discussing risks, benefits and limitations of an invasive procedure is quite familiar to most

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue **June 15**Submission deadline **May 10** 

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health care providers. Patients have learned to expect consultation visits prior to surgery, chemotherapy and other major procedures.

Similarly, the genetic counseling visit prior to an invasive prenatal test has become the norm. However, genetic testing procedures are becoming minimally invasive...a blood draw, a finger stick and a Guthrie card, a cheekbrush. Health care providers and patients are not accustomed to an indepth conversation or a signed consent prior to these types of procedures. The ease of these methods of obtaining cells is deceptive because the results of the genetic tests can have wide sweeping implications, encompassing not only the patient's condition but also his view of himself. The results may affect his family, and he may fear it will affect his insurability, his career and his other relationships.

We must encourage health care providers to recognize the unique nature of genetic testing and the importance of informed decision making and pre-test discussions. Consumer and health care provider education is critical to this process, and we hope that the education working group will address this issue as well.

#### RESULT REPORTING

Another key issue is result reporting, which depends on knowledgeable clinicians and clear laboratory reports. Genetic counselors are intimately involved in the interpretation of genetic lab results and are often consulted by other health care providers to assist in deciphering them. We can attest to the conclusions of research, which show that results can be misinterpreted by clinicians unfamiliar with genetic testing.

Paramount to the accurate provision of genetic test information is a lab report that provides the analytical and clinical validity of the test in clear, straightforward language. We encourage the SACGT to develop guidelines for laboratories to standardize the terminology used in test reports. Lab reports should clearly indicate affected vs. carrier vs. predictive results. Penetrance, variable expression and genotype-phenotype correlations should also be clearly discussed. A clinician's ability to accurately communicate test results is directly related to the clarity of the information contained within the report and the clinician's understanding of the disorder in question. The SACGT can play an important role in the support of both these ends.

#### ACCESS TO CARE

Finally, we encourage the SACGT to address the issue of access to genetic services. Genetic counselors are committed to access to care to all individuals, both for genetic counseling and genetic testing. In fact, we adopted a position statement specifically addressing this issue, a decade ago, in 1991.

Genetic counselors must often contend with the logistics of genetic testing, including obtaining insurance authorization for genetic testing. Our experiences uncover a fundamental inequity in the availability of genetic testing. Privately funded insurance carriers have come a long way in understanding and See SACGT, p. 6

### RESOURCE

Complete Proceedings of SACGT meeting

www4.od.nih.gov/oba/sacgt.htm

### SURVEY DATA AUGMENTED

In follow-up to the 2000 Professional Status Survey report which appeared in the last issue of *Perspectives* (Supplement, Vol 22, No. 4), many members requested that salary data be analyzed by both region and years of experience. Also, requests have been received from individuals with PhDs who were interested in salary data.

### Region and Years Experience

The following six tables include Mean, Minimum and Maximum salary reported by full members with Master's level degrees working full-time in the US or Canada (N=672). All Canadian salaries have been converted to US dollars. Categories with an N of five or less have been omitted in this report to protect confidentiality of respondents.

— Jennifer Farmer, MS Chair, Professional Issues Committee

Region 1 -	CT, ME	E, MA, NH,	RI, VT and	Nova Scotia
Yrs Exp	N	Mean	Min	Max
0-5	25	\$39,526	\$25,259	\$56,000
5-10	16	\$46,587	\$38,000	\$60,000
10-15	6	\$48,833	\$41,000	\$56,000

Region 2 – DE, DC, MD, NJ, NY, PA, VA, WV, and				
Quebec, Puerto Rico and US Virgin Islands				
Yrs Exp	N	Mean	Min	Max
0-5	71	\$40,542	\$23,575	\$60,000
5-10	36	\$44,477	\$32,332	\$65,000
10-15	19	\$55,986	\$37,400	\$71,000
15-20	22	\$58,056	\$41,300	\$86,713
20-25	15	\$60,292	\$43,000	\$108,000

Region 3 – AL, FL, GA, KY, LA, MS, NC, SC, TN				
Yrs Exp	N	Mean	Min	Max
0-5	50	\$39,292	\$32,000	\$52,500
5-10	18	\$43,064	\$36,732	\$57,000
10-15	11	\$48,375	\$41,225	\$63,500
15-20	7	\$47,051	\$39,983	\$52,000

Region 4 – AR, IL, IN, IA, KS, MI, MN, MO, NE, ND,				
OH, OK, SD, WI and Ontario				
Yrs Exp	N	Mean	Min	Max
0-5	90	\$39,026	\$28,290	\$70,000
5-10	30	\$46,455	\$38,000	\$80,300
10-15	17	\$49,925	\$33,000	\$64,000

Region 5 -	AZ, CO	, MT, NM,	TX, UT, WY	Y and Alberta
Yrs Exp	N	Mean	Min	Max
0-5	41	\$38,807	\$26,741	\$65,000
5-10	15	\$45,049	\$38,230	\$57,700
10-15	9	\$50,819	\$35,500	\$73,600

Region 6 – AK, CA, HI, ID, NV, OR, WA and British					
Columbia					
Yrs Exp	N	Mean	Min	Max	
0-5	68	\$46,614	\$33,000	\$65,000	
5-10	26	\$54,109	\$36,000	\$95,000	
10-15	20	\$58,668	\$41,000	\$80,000	
15-20	14	\$59,683	\$45,000	\$84,000	

PhD Data					
The following salary data is for individuals with a PhD					
who a	who are working full-time in the US or Canada.				
N	Mean	Min	Max		
20	\$55,432	\$35,000	\$90,000		

### SURVEY: NEW GRADS JOB SEARCH

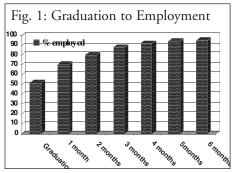
### Martha Shaw Dudek, MS & Patricia Robbins-Furman, MPH

Are recent graduates of genetic counseling programs finding jobs? NSGC's Membership Committee wanted to answer this question and explore job search experiences of recent graduates. A questionnaire was mailed to 1997, 1998 and 1999 graduates of master's level genetic counseling training programs. Of 410 questionnaires mailed, 206 were returned, a response rate of 50%.

### WHAT IS THE JOB OUTLOOK?

- The mean length of time to find employment was 1.3 months after graduation.
- A majority of graduates (52%) had accepted a position prior to graduation. Of the remaining graduates, the mean time to find employment was 3.4 months (median = 2) after graduation.

Figure 1 illustrates the cumulative percentage of respondents who were employed by months since graduation.



# How are Graduates Finding Jobs?

The most utilized and helpful resources for seeking employment were, in descending order:

- Networking
- NSGC JobConnection (Listserv and *Perspectives*)
- NSGC's Annual Education Conference

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## PERCEPTION OF TRAINING PROGRAMS

- 90% of graduates indicated that their programs did not have formal job placement services.
- 74% indicated that their programs had informal networks for job placement.
- 67% indicated that their programs provided "other assistance," e.g., resume writing or interviewing skills.

### NSGC'S PERCEIVED HELPFULNESS

- 91% attended NSGC's Annual Education Conference prior to graduation.
- 77% indicated that they used the NSGC listserv in their job searches.
- 70% stated that they had learned of job opportunities not posted with NSGC.
- 9% who distributed resumes at NSGC's Annual Education Conference were offered jobs as a direct result of networking at the meeting.

# WHAT ARE THE CHARACTERISTICS OF DESIRED JOBS BY GRADUATES?

- The majority (71%) of respondents ranked location as the most important characteristic of their desired jobs. Eighty-seven percent had specific geographic preferences when looking for a job.
- 75% of respondents indicated they were able to obtain a job in their "city of choice."
- Specialty (prenatal, pediatric, adult or cancer) was ranked the second most important characteristic while salary was most frequently ranked third, with setting (private vs. academic) as the least important.

#### IN SUMMARY

The results of this survey are encouraging and show that the majority of new graduates are finding jobs quickly and in their desired location. •

### SURVEY: WHY...

### Bonnie Hatten, MS

In July 1999, the Membership Committee sent an exit interview survey to former NSGC members who left the Society in 1998 or 1999 to assess their reasons for leaving and to determine if changes could be made to retain members. A total of 203 surveys were sent with a response rate of 23%.

### **DEMOGRAPHICS OF RESPONDENTS**

For those 37 respondents working or previously working as genetic counselors, the average age was 39 and all but one graduated from a genetic counseling training program in the 1980s or 1990s. The average number of years working as a genetic counselor was 7.6. Fifteen were employed as genetic counselors, 19 were not working and three did not answer.

When asked about previous involvement in the organization, 29 (78%) indicated no involvement.

### RETENTION ISSUES FOR COUNSELORS

When asked about the advantages of membership, the most common responses were similar to reasons for joining:

- keeping current
- access to Journal and Perspectives
- membership directory and
- decreased conference fees.

### Disadvantages were:

- cost and
- none.

When asked for the reasons for leaving, 30 (81%) responded that they were leaving the profession, about one third of those for family reasons; 25 (68%) responded that there were no unmet expectations that contributed to their leaving NSGC.

Three overseas members indicated the inability to pay by credit card as a problem. Two of the total respondents indicated disappointment in the quality of information in the *Journal*.

When asked if they would rejoin, 26

### ...MEMBERS LEAVE

(70%) replied that they would, probably when they returned to work or if the costs were lower.

When asked What changes could the NSGC make to retain members?, eight responded that no changes were necessary, 16 did not answer, six listed a lower cost and two suggested a lower fee for being on the listsery only or for non-working members.

### RETENTION ISSUES FOR OTHERS

Ten additional respondents who are not working in genetic counseling listed occupations such as nurse, computer analyst, teacher and bioethics director. Reasons cited for inactivating memberships among these individuals were (respondents could check more than one): leaving the profession (5), lack of job opportunities, especially for males (3) and financial reasons (3). One responded that "news and publications became too incestuous, lack of innovation in philosophy" and another "expected more open mindedness and broader view of the role of genetic counselors in society."

### IN SUMMARY

In evaluating the comments, the majority appeared to be leaving for reasons other than dissatisfaction with their membership. Responses from individuals working as genetic counselors indicated change of personal or financial status as major issues for not rejoining. For nongenetic counselors, feelings of not belonging headed the list. ❖

### FYI NOTES TO MEMBERSHIP:

In 1998, NSGC explored the possibility of accepting credit cards. At that time, the cost to NSGC would have been 3% of each transaction, plus overhead for processing. We are revisiting the feasibility of accepting credit cards for '02.

Regarding alternative memberships, we currently offer newsletter, only, subscriptions for \$25/year. �

### **EVALUATING WEB INFORMATION**

### Kathleen Fergus, MS

website may give you some idea of the validity of the site, evaluating the content provided by a website can be more complicated. There are some strategies, ranging from using common sense to doing a little detective work, which can help tell the good from the bad.

### **COMMON SENSE**

Is the site well written? If a website contains misspelled words, poor grammar or other forms of bad writing, the webmaster may have skimped on the fact checking as well.

#### BUYER BEWARE

Sites that are selling something have a built-in motivation to use biased information. If you cannot distinguish the information from the advertising, then you should be highly suspicious that the site may contain biased, if not incorrect, information.

### LANGUAGE

Looking at some of the verbs used on a webpage can give you some clue to the validity of the medical information on that site. You should start to get suspicious about the factual nature of the content if you see opinion verbs such as claims, believes, argues, feels, thinks, considers, presumes or assumes. Factual or scientific language usually contains verbs such as proven, shown, demonstrated, confirmed, validated or verified.

#### MORE LANGUAGE

Sites that contain words or phrases such as conspiracy, secret, plot, magic, ancient, "act quickly", "limited number" and "cures all" should be suspect.

While looking on the surface can give you some idea of site validity, a little more detective work can also give you clues to the accuracy of the medical information on the site.

### COMPARISON SHOP

Information from the Internet should never be looked at in isolation. You should always check reference books or journal articles and make sure that the information matches. In addition, surf the Internet for other webpages on the same topic to see if they contain similar information or claims.

### **QUESTION AUTHORITY**

While many sites purport to be written by medical professionals, it is important to check their credentials. A Dr. can be an MD, PhD, psychologist, veterinarian or biochemist! Their affiliations should be clearly stated on the website, but if not, it is possible to do a little detective work. One technique is to check the website of the appropriate medical subspecialty board, most of which have a searchable membership roster (try the American College of Medical Genetics). Another possible technique, if the author has a relatively rare name, is to use a search engine to see what else the author has written on the Internet.

## Don't Be Fooled by Glitzy Awards

There are lots of organizations that award "seals of approval" to medical websites. The criteria behind these "awards" vary quite dramatically and some of these "awards" can actually be purchased! If you see one of these symbols, you should be able to click on it and be taken to the awarding website that contains the criteria of the awarding body. Decide for yourself if their criteria are strong enough. •

### WRITING A QUALITY ABSTRACT

Susan Estabrooks, MS

The decision to have the Annual Education Conference (AEC) as a stand-alone meeting has resulted in a commitment to improve the quality of abstracts and overall research that is presented at the AEC. The following information was taken from a 1988 article by Edward Clark entitled "Writing an Abstract for a Scientific Meeting," *AJDC* 142: 422-424, and will help you write your abstract for the next AEC (deadline June 15; see page 7).

#### DECIDE ON THE MESSAGE

The first step in writing is deciding which one or two points are most important to present. The work must be original and not previously published as a manuscript and cannot be based on anticipated data. As different professional groups require different information, always follow instructions provided in the conference materials exactly. Abstracts should be written at least four weeks prior to the deadline, allowing time for corrections and review by authors. Only substantial contributors to the project should be co-authors. The first author is the person who did the majority of the work, the last author is usually the senior member who provided overall direction to the project and each coauthor must review and approve the abstract.

### **TENSE**

Use the present tense when referring to previously published work, since it is peer reviewed and accepted as general knowledge (e.g. genes are made of DNA). Use the past tense for unpublished work (e.g. cholesterol increased with increased fat intake), and use the active voice and first

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person (e.g. we measured lung function using a spirometer) for the current work being described.

#### **O**RGANIZATION

Proper organization is perhaps the most important consideration when writing an abstract, enabling the reader to follow and appreciate the research presented. Although there are many different styles, Clark suggests:

- Start with a one sentence statement of the problem, a statement describing why someone should be interested in the research.
- Follow with a one sentence hypothesis, purpose or intent, and a description of how the project was organized. The hypothesis usually describes something that can be accepted or rejected, as in most quantitative research; the purpose or intent may be more useful in a descriptive study or qualitative research.
- Proceed with "methods and theoretical approach" section, which is generally 1/2 to 1/3 of the abstract, and tells the reader what is being done. This section reports on the study population and how it was selected. The statistical analysis and measurements used to test the hypothesis are described, if relevant.
- Report results in a concise and consistent manner. If three different measurements are provided, then results should be given in the same order.
- Conclude with one sentence that reviews the implications of the research as it relates to the intent of the study. For case reports, lessons learned and/or recommendations for others are summarized.

With these tools in hand, we hope you will enthusiastically get to work on your submission for our upcoming AEC in Washington DC! ��

### SACGT from p. 2

authorizing appropriate genetic studies, resulting in easier access for their members. When insurance does not authorize testing, many consider paying for services out-of-pocket, depending on the individual patient's needs and ability to pay.

Patients insured through Medicaid/ Medicare funding, however, are often denied coverage for genetic testing and counseling, and are least able to turn to their own financial resources to procure appropriate care. This dilemma is compounded when the testing in question is done in only a limited number of laboratories, none of which is specifically involved in the capitation agreements associated with many Medicaid/Medicare coverage suppliers.

Another dilemma may arise because genetic testing often depends on studies done on extended family members, but insurance plans will often cover testing for the index patient only.

Access to genetic services should not be determined by a patient's socioeconomic status. This gap between the wealthy and the poor is not unique to the realm of genetic testing, but the SACGT can help to narrow this gap by supporting education efforts to be directed at Medicaid/Medicare administrators, medical directors and case managers.

In summary, the National Society of Genetic Counselors applauds the efforts of the SACGT and is committed to assisting the committee in its work to evaluate the oversight of genetic testing, test classification, consumer and health care provider education.

We are committed, as well, to ensuring informed decision making and informed consent, clear communication in result reporting, and access to care for all individuals regardless of socioeconomic status.

### '01 CONFERENCE UPDATE

November 4 - 7, 2001 (Registration begins Nov 3)

Current Advances — Anticipating Change

MINI-COURSES

Registrants at this year's conference will choose among these 4-hour, intensive learning sessions

A. Disability and Genetic Counseling at the Interface. Enhance your awareness of personal and professional reactions to issues of disability and review disability history and models.

B. Business 101: Negotiating and Effective Influencing. Understand the bottom line in the business of genetics. Examine effective negotiating skills, facilitate meetings, write a business plan and manage people and resources.

C. Genetic Counseling for Adult Cardiovascular Disease. Leap ahead of the curve! Explore your potential role in counseling and educating families with adult onset cardiovascular disease. Identify support networks, clinical and basic science research projects and registries.

D. Issues and Challenges of Genetic Education, Testing and Counseling in the Native American/Canadian First Nations Populations. Expand your skills by converging your knowledge base in genetics and genetic counseling with specific issues related to Native American and Canadian First Nations cultures.

E. Past and Current Status of Genetic Legislation and Laboratory Regulation — What A Genetic Counselor Should Know. Investigate the status of legislative issues involving genetics and the various effects on different government and non-profit organizations as they apply to genetic testing.

ABSTRACTS

Submit abstracts electronically by Friday, June 15 at 11:59pm EST. Notification regarding acceptance will be sent by July 16.

Visit www.nsgc.org click on <About NSGC> or <Members' Corner> then <Educational Programs>. Click on the "Abstract Submissions Online" link.

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— or — Susan Estabrooks, MS,

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SHORT COURSE

Counseling and Management of Metabolic Disorders,

Nov 7-8. This conference will provide a comprehensive review of a variety of inborn errors of metabolism. An emphasis will be placed on understanding the status of current biochemical and molecular testing options as well as recent advances and protocols for testing during pregnancy, the newborn period and post-mortem screening. Medical management, treatment and counseling strategies will also be addressed. ��

### WHAT'S NEW FOR '02

Our 21<sup>st</sup> Annual Educational Conference theme is *Genetic* Counseling: Coming of Age in the Technology Era, in Phoenix, Arizona, Nov 10-13, 2002. A Short Course will precede the conference, Nov 8-9.

Our conference is a great way to become involved in NSGC. Take the plunge and contact any of the following chairs:

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### CALL FOR PROPOSALS

The Special Projects Fund provides an annual award of \$5000 for projects that focus on the future of the genetic counseling profession and/or improving the provision of genetic services. The fund is an opportunity to enhance professional development.

Project proposals must be submitted by May 15 by NSGC members in good standing. Student thesis projects cannot be funded. Awards are based on the proposal's strength and feasibility, as judged by the Special Projects Fund Committee. The winners will be announced at the Annual Education Conference in Washington DC.

### PREVIOUS AWARD PROJECTS

- 1998 E. Matloff: Impact of Cancer Genetic Counseling on Providers
- 1999 J. Habecker-Green: A Study of Attitudes toward Diagnosis in Pediatric Genetic Counseling
- 2000 R. Bennett: Recommendations for Genetic Counseling and Screening of Consanguineous Couples and their Offspring
- 2001 B. Lerner: Current Issues in Genetic Counseling: Interactive Internet-based Continuing Education Program for Genetic Counselors.

The '01 Special Projects Fund Committee includes: Michael Banke, Amy Bazyk, Jeanne Homer, Lisa Jay Kessler and ex officio, Teresa Brady and Nathalie McIntosh.

A call for proposals was sent to all members in the Winter membership mailing.

Peter Levonian, Committee Chair, ©608-782-7300,x3995; plevonia@gundluth.org or visit: www.nsgc.org/members/mem\_special\_projects\_fund.asp ❖

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### The Larger Genetics Community

# EDUCATION COMMITTEE IDENTIFIES PROFESSIONAL EDUCATION

Simon Goldberg, MS & Terri Creeden, MS

The Professional Education Subcommittee within NSGC's Education Committee is charged with communicating important professional education efforts that are currently underway. Hopefully this will foster further NSGC involvement with these projects.

### **HuGEM**

The Human Genome Education Model Project II (HuGEM) is a joint project established by Georgetown University and the Genetic Alliance, and is funded by the National Human Genome Research Institute's (NHGRI) Ethical, Legal and Social Issues (ELSI) program.

HuGEM II is composed of seven collaborating allied healthcare provider groups:

- American Occupational Therapy Association
- American Dietetic Association
- American Psychological Association
- American Physical Therapy Association
- American Speech-Language-Hearing Association
- National Association of Social Workers and
- Council on Social Work Education.

Professionals belonging to these associations serve patients with primary concerns other than those related to genetics. However, genetic issues often arise during their patient consults. Thus, two important questions for this group are: "How much genetics knowledge do these professionals require?" and "How can they be appropriately educated about genetics in terms of the scope of their practices?"

This project has involved surveying the seven groups and then providing genetics education products to help bolster their clinical knowledge.

### **NCHPEG**

The National Coalition for Health Professional Education in Genetics (NCHPEG) was formed in 1996 by the American Medical Association, the American Nurses Association and NHGRI. This coalition includes more than 100 diverse health professional organizations representing all areas of health care including: consumer, voluntary, government, private, managed care and genetics organizations.

Its goals are to integrate genetics content into all allied health care professionals' curricula and thus increase the genetics knowledge base of health care professionals, most of whom are not primarily trained in the field of genetics.

In the past year, NCHPEG has named its first Executive Director, Joe

McInerney, who is a member of NSGC. Robin Bennett serves as NSGC's liaison to NCHPEG. ❖

#### RESOURCES

- \*\* HuGEM www.georgetown.edu/research/hugem
- Genetics In Medicine, July/Aug 2000 Vol2(4)226-231
- NCHPEG www.nchpeg.org

### RESEARCH NETWORK

## PASTORAL ROLE AS PARTNER TO GENETIC COUNSELING

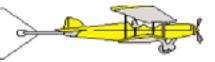
The Park Ridge Center for the Study of Health, Faith, and Ethics, with a grant from the Ethical, Legal and Social Implications (ELSI) branch of the Human Genome Project, is conducting research to

identify and analyze the nature and extent of the pastoral counselor's role in genetic counseling as understood by genetic counselors and other healthcare professionals.

The research will inform health care organization leaders, clinical professionals and religious educators

sal2012@med.cornell.edu �

### Media WATCH



Angela Geist, MS and Roxanne Ruzicka, MS

USA Today (12/1) — "Routine amnio for older women not needed" discussed the *The Journal of Obstetrics & Gynecology* article which recommends using the triple screen rather than maternal age in determining who needs an amniocentesis. The article correctly points out that this approach does not benefit women who want information earlier in pregnancy and pursue CVS.

Washington Post (12/2) — "Ignorance Undercuts Gene Tests' Potential" described the complexities of genetic testing and conveying genetic test results and how this process is complicated by physicians who are not knowledgeable in the field of genetics. Genetic counselors are described as the best trained professionals to describe genetic tests and interpret results, but it is stated that there are not enough genetic counselors to handle the demand.

American Medical News (12/25) — "Genetic Tests Need to Prove their Value." This article described that genetic counselors "are used primarily in reproductive medicine, although experts predict their role will expand rapidly beyond that specialty in the future." The article discussed the increased demand that is expected in the future for genetic counseling and testing because "everyone's at risk for something." The author expressed concerns (albeit not entirely correct) about genetic counseling and testing as well: "Genetic counseling and genetic tests are rarely reimbursed and there is a real fear among patients that the information will be used to their detriment ..."

"Today Show" (1/22) — Prenatal testing options, including amniocentesis, CVS and triple screen as well as genetic counseling were accurately discussed. It was pointed out that despite the fact that CVS is generally considered to have a higher risk than amniocentesis, at centers with experience, the risk of CVS is close to or the same as that of amniocentesis, making it a good option for many women. Katie Couric mentioned that there are genetic counselors in most large facilities to help couples explore their options.

"Living with Risk: The Genetic Frontier" (1/23) on South Carolina Educational Television — A panel of experts in genetics — including Janice Edwards, MS— ethics, insurance, law and industry discussed the ethical and legal ramifications of the information that has been and will be obtained through the Human Genome Project. Topics discussed included the medical benefits of genetic testing, privacy, confidentiality, the availability of genetic testing and the potential for genetic discrimination. This program will be seen on local PBS stations later this year. �

the current and potential roles of pastoral counselors, ideal or expected roles they could play and ways in which institutional and professional practices can respond to the religious issues raised in connection with genetic testing and therapies.

We are now setting up confidential telephone focus group discussions with genetic counselors across the US, moderated by Professor George Balch, of the University of Illinois. Each session will last about 90 minutes and will be conducted in April or May at times convenient to participants.

Participants will each receive \$125 after their session.

Sarah Shockley ©888-325-7210 or ©510-237-2213; SHOCKLEY@lmi.net ❖

### **ALZHEIMER'S STUDY**

Weill Medical College of Cornell University is conducting a study called "Genetic Risk Assessment and Counseling for Alzheimer's Disease." The study explores the impact of providing individuals with a genetic risk assessment of developing Alzheimer's Disease using family history, age, gender and APOE genotype.

Participants must have a parent who is/was affected with Alzheimer's Disease and no signs of cognitive impairment or depression.

Susan LaRusse, MS, Department of Neurology, Cornell Medical Center, New York NY ©212-746-6580;



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Assess Your True Risk of Breast Cancer

Author: Patricia Kelly, PhD Publisher: Henry Holt and Co Cost: \$15.00 (paper). 253pp. Reviewer: Elizabeth Hoodfar, MSc

Tore and more of us are involved Lin cancer risk assessment, either as specialists, or integrated as part of our general practice. Most commonly we engage in risk assessment for breast cancer, in part due to its prevalence, and in part due to its high public profile. We often find contradictions and controversies about breast cancer risk factors in the medical literature and sensationalized inaccuracies in the media. We understand why our patients may be confused, anxious and afraid. We do our best to explain breast cancer risk and put the scientific information in context for them. Assess Your True Risk of Breast Cancer takes a giant leap in providing such explanations and contexts. This book tackles the mysteries of epidemiology and statistics and teaches the reader how to use them as tools to assess the importance and relevance of risk information. A tall order, Patricia Kelly accomplishes this goal skillfully and lucidly.

This book is truly comprehensive. "Part I: The Human Part" is devoted to the emotions breast cancer stirs up, such as anxiety, fear, guilt and beliefs about survival.

"Part II: Just the Facts, Ma'am" covers what's known and unknown about various breast cancer risk factors. Every chapter uses simple, easy-to-read language. Mathematical and statistical concepts are explained with clear and concise examples. Kelly also takes care to define and clarify

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# RESOURCES

biological and medical terms and concepts. Her complete coverage of the topic includes discussion of paternal family history, male breast cancer, relative risk, heterogeneity and the two-hit hypothesis. At the end of each chapter she provides a summary of "Key Points to Remember," which is extremely useful to the lay reader.

In presenting the scientific information, Kelly provides data from major research studies on each subject, carefully critiquing the study design and methods, reducing the statistics to meaningful practical numbers. Every figure provided is meticulously referenced. Summary charts are given for large studies with many variables and outcome measures. All of this is done in a disarmingly simple yet thorough manner, taking care to repeat key points. For instance, on benign breast disease, Kelly repeatedly gives risk per year for DCIS/LCIS/ atypical hyperplasia. She consistently points out that as each year passes, a woman leaves behind the risk for that year. The chapter on hormone replacement therapy miraculously makes sense of a body of scientific literature that has even medical professionals confused.

"Part III: Using the Facts" addresses topics such as risk assessment models, genetic testing and guidelines for making decisions about Tamoxifen, Raloxifene and prophylactic mastectomy. My favorite section is "If I were your relative?", which explains why posing this question to health care providers is not useful. Part III has examples and vignettes to illustrate the points.

Although genetic testing for breast cancer risk is discussed in more than one place, Kelly does not make it a goal to cover this topic comprehensively. But like a true



medical geneticist, she makes the point that genetic testing should be explored within the context of a full risk assessment service.

Assessing Your True Risk of Breast Cancer includes an appendix of questions "to determine if you might benefit from cancer risk assessment," web sites and organizations to go to for more information (including NSGC) and a glossary.

This is a book that has something to offer everyone, from the average woman to any health care provider who may be asked about breast cancer, to the seasoned cancer genetic counselor. For the professional, it is a quick read, guaranteed to make a light bulb go off in your head at least once. I have already used the knowledge and insight from this book in my practice.

This is a must read for genetic counselors specializing in breast cancer risk assessment and a book well worth recommending to patients. •



Prenatal Testing and Disability Rights

Editors: Erik Parens & Adrienne Asch

Cost: \$23.95 pp. 371

Publisher: Georgetown University Press, Washington DC, 2000

Reviewer: Kathy Morris, MSSW

This volume is a collection of papers written by members of a Hastings Center project which took up an ethical issue related to prenatal diagnosis: the "disability rights critique." The "critique" asserts that the existence of prenatal diagnosis (with the implication that fetuses with disabilities will be aborted) sends a hurtful message to and about those with disabilities. Termination of pregnancy for disability, critics argue, reflects prejudice and ignorance about what life with a disability is like for affected individuals and their families.



The book is divided into four sections. The first section summarizes the Hastings Center project, synopsizes the disability rights critique and reviews the current status of prenatal testing in the US. Parts two and three offer a variety of perspectives on the disability critique, including contributions by disabled individuals, family members, scholars who have done research with families of disabled individuals, a parent who had prenatal diagnosis, philosophers and ethicists. Part four takes up questions of policy and service delivery, featuring essays about whether and how to limit prenatal testing and the interface between prenatal testing and the courts. The final chapter offers thoughts on how genetic counseling might be influ-

# RESOURCES

enced by the disability rights critique.

A recurring theme is the complex and contradictory feelings people hold about disabilities. There is tension in simultaneously respecting and valuing people with disabilities and endorsing prenatal testing and parents' decisions to terminate pregnancies. These contradictions are evident in many essays in this book, including papers by those with personal experience with disability. Most eloquent is an essay by a blind woman whose husband expresses relief when he learns that their children will not likely be blind. Her pain and confusion at his reaction are poignant.

Another interesting theme was the larger medical "system" and its

Price: \$59.95

Human Molecular Genetics II Authors: T. Strachan & A.P. Read Publisher: John Wiley & Sons, NY 1999 ISBN: 0471330612

Reviewer: Shelly Cummings, MS

Tdeally, all health professionals should have a fundamental understanding of Lthe impact of genetics on human health and disease. Strachan and Read have updated their 1996 edition of Human Molecular Genetics in a manner that explains a complex field in an easy to understand manner. This complete account of human molecular genetics ranges from basic to very high levels of understanding.

Human Molecular Genetics II is an authoritative, integrated and fully updated edition of a classic reference on human molecular genetics. This edition clearly explains the structure, function and evolution of the human genome, covering the topics of cloning, mapping and genetic diseases. In addition, this comprehensive text includes the latest Human Genome Project data, how to obtain data from web-based resources, new color figures and expanded coverage of common diseases.

The chapters covering hybridization, imprinting and positional cloning are clear and include graphically detailed illustrations. In addition to the book index there is a separate and very extensive "Disease Index." While the concept of genetic counseling is mentioned, there is no mention of the field of genetic counseling. One might say this omission is a side effect of both authors being from the UK. However, I was disappointed particularly given that there are other texts of this same caliber that have entire chapters on our profession and its value to the medical community.

Overall, however, I would highly recommend this resource to students or professionals who are familiar with genetics but need to understand the practical side of it. \*



influence on provision of prenatal diagnosis. Nancy Press, a public health professor, offers one of the more readable assessments of the disability critique and provides a thought provoking perspective on the "system." Press notes that the powerful industries of research and medicine have a financial stake in continued provision of genetic tests, including prenatal tests. She correctly observes that much of medical practice (including recommendations for prenatal tests) is driven by the spectre of malpractice lawsuits. Press ponders the role of genetic counselors in prenatal diagnosis, questioning whether our utility is to our patients or the system in which we work.

There were two conspicuous omissions throughout this book. First, in discussing termination of pregnancy for "disabilities," most authors fail to acknowledge the huge variation in prognosis for prenatally diagnosable conditions. It does not seem reasonable to assess the "message" of prenatal testing without considering distinctions between such diagnoses as Tay Sachs and Turner syndrome, anencephaly and deafness. Similarly, the value of prenatal diagnosis for purposes other than abortion is barely acknowledged.

While there is much repetition (e.g. many authors acknowledge the reality of discrimination and prejudice against individuals with disabilities) and some chapters were dense with complex ethical arguments, I found this work intriguing and enlightening overall. Prenatal counseling can become routine if we let it. This book will challenge prenatal counselors to re-evaluate our practice and to stay mindful of how our work might be interpreted. �



# **BULLETIN BOARD**



UTAH BECOMES 2<sup>nd</sup> STATE TO LICENSE GENETIC COUNSELORS Vickie Venne, MS

Inder the able leadership of Christine Miller, the 14 genetic counselors in Utah have successfully achieved the first step toward professional recognition. Senate Bill 59, Licensure of Genetic Counselors, passed through both the Senate and House with clear majorities in February 2001. It is expected that this summer, a committee of five (four genetic counselors and a member of the general public) will be appointed to finalize the rules for licensure and then begin accepting applications.

Now the second step is to petition the payers and continue working toward those pesky CPT codes. �

### **ACMG REIMBURSEMENT** MANUAL NOW AVAILABLE

Tf you are a member of the American **▲** College of Medical Genetics (ACMG), you have received ACMG's newlypublished Manual on Reimbursement for Medical Genetics Services.

If you are not an ACMG member and attended the billing and reimbursement workshop at our Annual Education Conference or are simply interested in receiving a copy, NSGC has a limited supply. Orders will be taken as the supply lasts or until April 20, at which time all remaining copies will be returned to ACMG.

Send a check for \$5, payable to NSGC, postage and handling, to Lisa Brodeur, NSGC, 233 Canterbury Dr, Wallingford PA 19086. ❖

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### Nominate a Leader

N Tominations for the Regional Leadership Awards and Natalie Weissberger Paul Award are due by April 10.

Jennifer Farmer, 29 Bryn Mawr Ave, Newtown Square, PA 19073; Fax: 215-614-0298, or online: www.nsgc.org, click on Members' Corner, then click on the NSGC Awards link.

Tominations for the 2001-2002 Board of Directors, including President-elect and Representatives to Regions I, III & V are due by April 6.

Cheryl Harper, charper@beaumont.edu or online: www.nsgc.org/members/online nomination\_form.asp �

### VOLUNTEERS WANTED

The Social Issues Committee is ■ looking for one volunteer from each state with an interest in legislation to help keep the membership aware of what is going on in your state that impacts the genetics community.

Karen Eanet @410-828-3131; keanet@abmc.ora �



### MEETING MANAGER

Mar 30-31

Region V Conference, "Poco de todo — A Little Bit of Everything," Santa Fe NM. © Cathy Wicklund: ©713-704-5110; Catherine.A.Wicklund@uth.tmc.edu

Region III Educational Conference, "Expanding our Mar 31 Horizons," Columbia SC. 0.625 CEUs. Lynn Holt: ©205-934-4973; lbaldwin@uab.edu

Apr 6 Region I Conference, "The Changing Face of Genetics: New Opportunities for Genetic Counselors," Auburn MA. This conference will focus on new career fields and requisite skills/strategies for Genetic Counselors. 0.5 CEUs. Ali Warner: ©508-832-8711; coordub@infi.net

Apr 20-21 Region IV Conference, "On the Horizon," Indianapolis IN. 1.0 CEUs. ™ Dawn Allain: €414-266-3047; dolloin@chw.org

Apr 20-21 Second International Anophthalmia/Microphthalmia (A/M) Conference, Chicago IL.

Mary Dwyer: 215-456-8722; gemcgenetics2@hotmail.com

Apr 23 Deadline for Electronic Abstracts for 31st Annual Meeting, Society for Neuroscience, San Diego CA, Nov 10-15. Apr 11 is deadline for paper submissions. There is a \$50 fee for www.sfn.org

electronic submissions.

Apr 24 - 28 58th Annual Meeting, American Cleft Palate-Craniofacial

Association, Minneapolis MN.

™ ACPA: ©919-933-9044; cleftline@aol.com

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NSGC / University of Pittsburgh Board Review Courses

for ABGC and ABMG Exams.

BWI Airport location, Baltimore MD May 31 - Jun 2

Jun 21-23 SFO Airport location, San Francisco CA

### **COMMITTEE & SIG UPDATES**

## '02 SHORT COURSE PROPOSALS Dawn Allain, MS

Proposals for '02 Short Course applications are being accepted through April 14, 2001. Members who have an innovative and high quality idea for a short course topic are encouraged to apply. Guidelines and applications are available.

Dawn Allain, Annual Education Conference Subcommittee Chair, ©414-266-3047; dolloin@chw.org ❖

### STUDENT SCHOLARSHIPS TO BE AWARDED Barbara Harrison, MS

To increase membership diversity, the Diversity Special Interest Group (SIG) and the Membership Committee have engaged in a joint effort to provide two \$200 scholarships to students planning to attend the 20<sup>th</sup> Annual Education Conference in Washington DC, this November. Genetic counseling students enrolled in the fall of 2001, and who are members of the NSGC, are encouraged to apply.

The Membership Committee scholarship is open to all students; the Diversity SIG scholarship is limited to students from communities underrepresented in NSGC.

Applications, with complete details, will be available in April and due in May. Information will be posted on the student listserv and distributed to the program directors.

Applicants will be asked to answer the following questions:

MEMBERSHIP COMMITTEE
Explain/describe some of the barriers that may face some populations that would prevent them from accessing or seeking genetic counseling services.
Make suggestions regarding how the NSGC and its members might help break down some of these barriers.

### DIVERSITY SIG

Describe an event in your past when you felt you were successful reaching out to someone from a culture other than your own. Discuss what made this interaction successful and what lessons from this can be applied to the daily interactions with our patients.

■ Barbara Harrison, Co-chair, Diversity SIG, ©202-806-6329; bfwillis@howard.edu ❖

# WHAT CAN THE NSGC ETHICS SUBCOMMITTEE DO FOR YOU? Logan Karns, MS

Ethical dilemmas are an integral component of genetic counseling. The Ethics Subcommittee is available as a confidential resource to all members of NSGC to help them work through challenging issues.

Appropriate topics for consultation include relationships between counselors and their clients, colleagues, society and selves. Initiate a consult by contacting any of the members listed below. In the near future we will be available as a direct link on the Members' Corner page of the NSGC web site.

lbk2t@virginia.edu Logan Karns, Chair kfitzge@luc.edu Kevin FitzGerald pLevonia@gundLuth.org Peter J. Levonian markel@umich.edu Dorene Markel kormond@nmh.org Kelly Ormond mroche@css.unc.edu Myra I. Roche Kathy Valverde valverde1@msn.com Yashar@umich.edu Beverly Yashar

# CONNECTIVE TISSUE DISORDERS SIG UPDATE Jamie Durkovic, MS

Connective tissue disorders are being diagnosed with increasing frequency. The clinical variability and genetic heterogeneity of these syndromes can be complex.

Our group is available to answer questions members may have about diagnostic criteria, testing and genetic counseling issues unique to this group of disorders. We are also available if your center is considering establishing a clinic, has a new clinic or needs our services as a consulting body.

Our Practice-based Symposium at the '99 Annual Education Conference focused on many issues faced by individuals who suffer from connective tissue disorders face. Due to the fragility of their connective tissue, concerns regarding chronic pain, self-esteem, sexuality, gynecology and pregnancy are common. We are able to respond to a wide range of questions from Beighton scores to bruisability.

We are planning another Practice-based Symposium for '02 addressing testing options and issues surrounding the diagnosis of connective tissue disorders. Let us hear from you if you have specific issues or conditions you would like us to address.

A group within our SIG is responsible for our information on NSGC's website, enabling us to provide updates on our progress, our plans for the future and contact information.

Lastly, we are actively recruiting those interested in connective tissue disorders. Related experience or work environment is not necessary ...just a desire to learn and understand this group of baffling disorders.

Michelle Moore, Chair
Michelle.Moore@MEMHOSPCS.org ❖

# CLASSIFIED

- Los Angeles CA: Immediate opening for FT or PT Genetic Counselor: case follow-up on repts of abnorm in preg or live births; i'view male applicants for anonymous semen donor prog, incl obtaining detailed info re applicant's personal and fam med hx & drawing fam pedigree. Marilyn Ray, MPH, California Cryobank, Inc, 1019 Gayley Ave, Los Angeles CA 90024-3401; @800-231-3373x21; @310-443-5244x21; Fax: 310-443-5258; mara@cryobank.com. EOE/AA
- SOUTHERN CA: Immediate opening for BC/BE Genetic Counselor. Coord Calif Expanded AFP Prog, a progressive, statewide multiple marker scrng prog in 4-regions of So. Calif. Daily contact w/ PN care providers assisting them to obtain follow-up svcs for pts; educ providers in commun; interact w/ follow-up PNDx ctrs & provide input into evolving field of PN scrng. Linda Healy, RN, Cedars-Sinai Medical Center, 444 S. San Vicente Blvd-Ste 1005, Los Angeles CA 90048; @310-423-9650; healyl@cshs.org. EOE/AA
- Orange CA: Immediate opening for BC Genetic Counselor w/ fac appt. PN genetics exp, excellent clin, i'personal & org skills req. Span desirable. GC at acad institution in various PN settings; tch & clin s'vision for GC students; tch med students, residents & other health prof; commun outrch.
- Send CV & 3 ltrs refs: Suzanne B. Cassidy, MD, Director, Div Human Genetics, Dept Pediatrics, UCI Medical Center, 101 The City Dr, Bldg 2, 3rd Fl-ZOT 4482, Orange CA 92868; ©714-456-6873. EOE/Excellence through Diversity.
- SACRAMENTO CA: Immediate opening for BC/BE Genetic Counselor. Exp. pref. Join estab, c'hensive HMO located halfway between San Francisco & Lake Tahoe. Provide broad range of PN, peds, CA & adult GC.
- Send CV & 2 ltrs ref: Jacqui Wright, Kaiser Permanente,1650 Response Rd, Sacramento CA 95815; Fax: 916-614-4768; jacqui.wright@kp.org. EOE/AA
- SAN DIEGO CA: Immediate openings for BC/BE Genetic Counselors. PN & preconcep GC. FT, PT & temp positions, relocation assist avail. Elaine Palome, MS, Staffing Consultant, Genzyme Genetics, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701-9322; ©508-271-3728; Fax: 508-872-2460; elaine.palome@genzyme.com. EOE/AA
- SAN FRANCISCO CA: See San Diego, Genzyme
- SAN FRANCISCO CA: Immediate opening for BC/BE Genetic Counselor. Ability to work i'pendently, excellent commun & org skills req. Exp pref. Spanish or Cantonese a plus. Join dynamic, diverse & growing PNDx Ctr & new cancer risk GC prog.
- Susan Millar, Manager, Prenatal Diagnosis Ctr,

California Pacific Medical Center, 3700 California

- St-#G330, San Francisco CA 94118; ©415-750-6400; Fax: 415-387-5876. EOE/AA
- SAN JOSE CA: See San Diego, Genzyme
- ATLANTA GA: Immediate opening for BC/BE Genetic Counselor. Enthus, dedicated prof in priv, acad Med Genetics Ctr. Exlnt verbal & written commun skills, computer-friendly, abil to travel. Resume & cover ltr, incl salary hx: Human Resources, GeneCare, PO Box 4270, Chapel Hill NC 27515-4270. No phone calls please. MJanas@genecare.com. EOE/AA
- GAINESVILLE FL: Immediate opening for BC/BE Genetic Counselor. Exlnt org & i'personal skills req. Join busy, univ-based reg'l genetics prog working w/ peds/adult pt pop. Opptys for tchg & rsrch. Coord onsite & sattelite clins. Heather Stalker, MSc, Div Pediatric Genetics, Univ of Florida, Box 100296, Gainesville FL 32610; ©352-392-4104; Fax: 352-392-3051; stalkhj@peds.ufl.edu. EOE/AA
- MIAMI FL: Immediate opening for Genetic Coordinator. ABGC or ABMG cert & min 5 yrs exp req. Expertise in public presentations essential; exp in oversight of educ activ a must. Coord educ activ, present & coord genetic info to public & prof audiences; work w/ faculty to assist them w/ presentations & provide educ supt material, e.g. slides & PowerPoint; work w/ web designer to estab interactive website of genetic info & links. Rodney Howell, MD, Acting Director, The Dr. John T. Macdonald Foundation Ctr for Medical Genetics, University of Miami School of Medicine, Dept Pediatrics, Mailman Ctr D-320, 1601 NW 12th Ave, 9th fl, Miami FL 33136; ©305-243-3993; Fax: 305-243-3990; rhowell@miami.edu. EOE/AA
- CHICAGO IL: Immediate opening for BC/BE Genetic Counselor w/ faculty appt. Exp pref. All aspects of PN GC in busy prac. Partic in tchg GC students & med residents. Marian Verp, MD, Dept OB/Gyn, University of Chicago Hospitals, 5841 S Maryland Ave, MC 2050, Chicago IL 60637-1470; ©773-702-6621; Fax: 773-702-5160. EOE/AA
- CHICAGO IL: Immediate opening for BC/BE Genetic Counselor. Exlnt org & i'personal skills req. Join a univ-based cardiovasc rsrch prog. Provide GC for adult cardiac/neuromusc clins. Elizabeth McNally, MD, PhD, Dept Medicine, University of Chicago, 5841 S. Maryland Ave, MC 6088-Rm. G611, Chicago IL 60637; Fax: 773-702-2681; emcnally@medicine.bsd.uchicago.edu.
- CHICAGO IL: Immediate opening for BC/BE Genetic Counselor w/ faculty appt. Exp in cancer GC strongly pref. Motivated, abil to work i'pendently & take initiative req. GC for hered BR & colon CA; signif involv in on-going devel of comp cancer genetics program. Opptys for prof & public educ, rsrch, tchg & s'vising GC students. Aimee Wonderlick, MS, Northwestern University Medical School, Dept Ob/Gyn, 333 East Superior, Ste 152, Chicago IL 60611; ©312-926-5737; Fax: 312-926-7638; awonderl@nmh.org. EOE/AA

- CHICAGO IL: Immediate opening for FT BC/BE Genetic Counselor. Enthus & dedicated prof w/ excellent verbal and written commun skills, computer-friendly & abil to travel. Join priv, acad Medical Genetics Ctr. ™ GeneCare, PO Box 4270, Chapel Hill NC 27515-4270. No phone calls. mjanas@genecare.com. EOE/AA
- EVANSTON IL: Immediate opening for BC/BE Genetic Counselor. Exp, abil to work i'pendently, exlnt clin, i'personal & org skills req. Cancer & adult genetics, prog devel, rsrch interest & exp req. Susan Nelson, Sr Director, Evanston Northwestern Healthcare, 1000 Central St, Ste 620, Center for Medical Genetics, Evanston IL 60201; ©847-570-2407; Fax: 847-733-5318. EOE/AA
- GARY IN: Immediate opening for BC/BE Genetic Counselor. All aspects of PN & genr'l GC: outrch clins; educ; newsltr & advisory board partic; tchg med students. Janice Zunich, MD, NW Center for Medical Education, Indiana University School of Medicine, 3400 Broadway, Gary IN 46408; ©219-980-6560.
- INDIANAPOLIS IN: Immediate opening for temp FT or PT BC/BE Genetic Counselor, from approx March to August 2001. Hosp-based MFM prac w/ 3 perinatologists: all aspects of PN & preconcep GC. GC in weekly peds clin oppty also avail. Teresa Brady, MS, Maternal Fetal Medicine, St. Vincent Hospital, 2001 W. 86th St, Indianapolis IN 46240; ©317-338-5027; Fax: 317-338-5052. EOE/AA
- BALTIMORE MD: Immediate opening for BC Genetic Counselor. Coord estab & growing PNDx prac w/ PN, Peds & adult GC: GC student s'vision, tchg, birth defects registry oversight. Karen R. Eanet, MS, Harvey Institute for Human Genetics, Greater Baltimore Medical Center, 6701 N. Charles St-Ste 2315 W, Baltimore MD 21204; ©410-828-3131; Fax: 410-828-2919; keanet@gbmc.org. EOE/AA
- BALTIMORE MD: Immediate opening for BC Genetic Counselor. Join univ-based team. Provide ped & adult pt svcs at hosp & satellite; involv w/ rsrch & tchng. CV & 2 ltrs rec: Michael Geraghty, MD, Johns
- Hopkins Hospital, Blalock 1008, 600 N. Wolfe St, Baltimore MD 21287-4922; @410-955-3071; Fax: 410-614-9246; geraghty@jhmi.edu. EOE/AA
- BALTIMORE MD: Immediate opening for BC Genetic Counselor. GC clin & rsrch respon on univ-based team for ped& adult pts at hospital & satellite clins. Manage Hirschsprung disease & congenital hydrocephalus fam studies: enrollment, informed consent, collect fam data & tissue samples & liaison w/ IRB. Send CV & 2 ltrs of rec: Colleen Swank, MS, Genetic Research Program Coordinator, Johns
- Hopkins Hospital, 600 N. Wolfe St Rm 2-109 JSB, Baltimore MD 21287-4922; @410-955-3071; Fax: 410-614-9246; cswank@mail.jhmi.edu. EOE/AA

# CLASSIFIED

- ROCKVILLE MD: Immediate opening for BC/BE Genetic Counselor. Local trav, exlnt i'personal and org skills req. Join GC & geneticist in busy PNDx/perinatology priv prac w diverse pt pop.

  □ Jill Fonda, MS, Center for Maternal-Fetal Medicine and Reproductive Genetics, 9707 Medical Center Dr, Suite #230, Rockville MD 20850; ©301-279-6355; Fax:301-279-6345; jfondo@adventistheolthcare.com. EOE/AA.
- BOSTON MA: Immediate opening for PT (32 hrs) BC/BE Genetic Counselor. Min 3 yrs exp. Join 2 GCs & 1 MD geneticist in busy multispec prac. PN & cancer genetics. Oppty for growth.

  Susan Mecsas-Faxon, MS or Martha MacMillin, MS, Genetics Dept, Harvard Vanguard Medical Associates, 133 Brookline Ave, Boston MA 02215; ©617-421-3320; Fax: 617-421-1063. EOE/AA
- BOSTON MA: Immediate opening for BC/BE Genetic Counselor. Partic in clin-molecular genetic rsrch into neuromusc disease. Coord pt ascertainment, enrollment & specimen acquisition for molec genetic studies on congenital myopathy & muscular dystrophy. Attend weekly clin, some trav. Send CV & 2 or 3 ltrs ref: Dr. Alan Beggs & Dr. Louis Kunkel, Genetics, Children's Hospital Boston, 300 Longwood Ave, Boston MA 02115; ©617-355-7574; beggs@toscol.med.horvord.edu. EOE/AA
- BOSTON, MA: Immediate opening for Genetic Associate. MS in GC or related field; some exp pref, not req. Busy molec DNA diagnostic prog, PN DX prog, involve in MSAFP prog; rsrch oppty avail. Newly avail: PN GC in hi-risk OB clin and partic in med genetics clin.

Aubrey Milunsky, MD, DSc, Center for Human

- Genetics, Boston University School of Medicine, 700 Albany St, W-408, Boston MA 02118; Fax: 617-638-7092; amilunsk@bu.edu. EOE/AA
- CAMBRIDGE, MA See Los Angeles, Calif Cryobank
- DANVERS MA: Immediate opening for .5 FTE BC/BE Genetic Counselor. Exp in PN req. Join Maternal Fetal Medicine Program.

   Julie A. Kautz Mills, Coordinator, Women's Health Center of the North Shore, North Shore Medical Center, One Hutchinson Dr, Danvers MA 01923; ©978-777-1070 x226; Fax: 978-774-9635; Pager: 978-445-3271. EOE/AA
- DETROIT MI: Immediate opening for BC/BE Genetic Counselor. Min 2 yrs exp pref. Join large, active team. C'hensive genetics svc: genr'l, peds, neuro, PNDx & abn U/S GC; field clins. Educ & pub opptys. Cyto, MSAFP, molec labs onsite.

  S Amy Decker, MS, Dept Medical Genetics, Henry Ford Hospital, 2799 W Grand blvd CFP-4, Detroit MI 48202; ©313-916-3188;

  Fax: 313-916-1730; odeckerl@hfhs.org. EOE/AA
- EAST LANSING MI: June '01 opening for BC/BE Genetic Counselor. Join large, multidisc team incl 2 GCs in univ-based genetics ctr: peds/genr'l genetics clinics, opptys in PN, cancer and HD clins, involve in DNA and PN scrng labs; working with students/residents.

  \*\* Rebecca Zoller, Michigan State University, B240 Life Sciences, East Lansing MI 48824; 
  \*\*©517-355-1297; zollere@msu.edu. EOE/AA

MINNEAPOLIS MN: Immediate opening for ABGC-BC/BE Genetic Counselor. Coord pt activ for genetics depts & clin; obtain med & fam hx;

interpret genetic dx; assess & commun risks; devel & provide educ svcs to health prof & lay grps.

Human Resources,
Fairview-University
Medical Center, 420
Delaware St SE, MMC
500, Minneapolis MN
55455; ©612-273-5550;
Fax: 612-273-1193;
fumchrl@foirview.org;
www.foirview.org. EOE/AA

■ MINNEAPOLIS MN: Immediate opening for BC Genetic Counselor. Primarily PN GC in suburban hosp settings w/ opptys to develop peds svc. Affil w/ clin genetics team at UMN. Opptys to s'vise GC grad stud & part in rsrch. Human Resources, Fairview-University Medical Center, 420 Delaware St SE, MMC 500, Minneapolis MN 55455; ©612-273-5550; Fax: 612-273-1193; fumchr1@fairview.org; www.fairview.org. EOE/AA

- ST LOUIS MO: Mid-June to mid-Sept opening for temp BC/BE Genetic Counselor to cover maternity leave. PN exp req. PN & preconcept GC in tertiary genetics unit.

  S Kay LeChien, MS, Washington University School of Medicine, Barnes-Jewish Hospital North, 216 S Kingshighway, St Louis MO 63110; ©314-454-8181; Fax: 314-454-7358. EOE/AA.
- HELENA MT: Immediate opening for BC/BE Genetic Counselor (Cancer Counselor). Join Med Genetics dept: ped & adult genr'l genetics, fetal pathology, PN & cancer. Act as a liaison to pts & prof for cyto, molec & maternal serum scrng labs. Outrch clins, travel, prof & public educ oppty.

  Submit Shodair Application, supplemental questionnaire, college transcripts: Gary Willis, Human Resources Dept, Shodair Hospital, PO Box 5539, Helena MT 59604; ©800-447-6614; Fax: 406-444-1035. EOE/AA
- LEBANON NH: Immediate opening for BC/BE Genetic Counselor. Exp in peds & PNDx pref. Abil to work i'pendently; exInt org, clin & commun skills essential. Join large multidisc team incl 4 GCs: ped & adult gen'rl genetics, PNDx & outrch.

  □ Dorothy Williams, Human Resources, Dartmouth Hitchcock Medical Center, One Medical Center Dr, Lebanon NH 03756; Fax: 603-650-8919. EOE/AA
- NEWARK NJ: Immediate opening for BC/BE Genetic Educator. High motiv, abil to work i'pendently, exlnt commun & org skills. Span pref. Maintain website on genetic educ; org & present genetic prog to MDs, commun grps; prov GC for wide range of PN & peds.

  EST Lorraine Suslak, University of Medicine and Dentistry of NJ, 90 Bergen St-DOC5400, Newark NJ 07103; 973-972-3311; Fax: 973-972-3311;

suslaklo@umndj.edu. EOE/AA

- New York NY: Immediate opening for BC/BE Genetic Counselor. Exp in cancer GC pref. Join leading team/center in cancer care & rsrch. All aspects of GC/case mngmt for pts & fam; partic in rsrch protocols in genetic epidem.

  Send CV & ref: Dr. Kenneth Offit, Chief, Clinical Genetics Service, Memorial Sloan-Kettering Cancer Center, 1275 York Ave-Box 192, New York NY 10021. EOE/AA
- NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Min 1 yr exp req. Provide PN & preconcep GC at 2 Manhattan sites. Opptys for growing peds & onc progs. Devel prof educ progs for attendings & residents.

   CV & Itr of interest: Elsa Reich, MS, or John Pappas, MD, New York University School of Medicine, 550 First Ave, New York NY 10016; ©212-263-6603 (ER); ©212-263-5746 (JP); Fax: 212-263-7590; elsa.reich@med.nyu.edu; igpappas@pol.net. EOE/AA

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national society of genetic counselors, inc.



the leading voice, authority and advocate for the genetic counseling profession

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# CLASSIFIED, from previous page

- CHAPEL HILL NC: See Chicago, GeneCare
- DURHAM NC: Immediate opening for BC/BE Genetic Counselor. Min 1 yr exp pref, enthus, motiv, i'pendent prof w/ good commun & org skills. Will consider new grad. Join active med genetics team to provide inpt ped consults & outpt evals in genr'l ped genetics, metab & multidisc clinics. Expanding opptys for diverse GC clin activ, coord, rsrch & tchg.

  Ser Send CV w/ 3 ltrs rec: Marie McDonald, MD, Duke University Medical Center, Box 3528, Durham NC 27710; ©919-681-1991/Jennifer Sullivan, MS. EOE/AA
- CLEVELAND OH: Immediate opening for BC/BE Genetic Counselor. Join 3 clin geneticists, 1 OB geneticist & 3 MFM spec: peds, adult & perinatal GC. Biochem, cyto, triple scrn labs onsite.

   Linda Vacha, Human Resources, MetroHealth System, 2500 MetroHealth Dr, Cleveland OH 44109; ©216-778-5785; Fax: 216-778-8905. EOE/AA
- COLUMBUS OH: Immediate opening for BC/BE Genetic Counselor. Exp pref; new grads encouraged to apply. Join an expndg acad peds grp. Assist MD clin geneticists in genr'l genetics clin, coord outrch clins and cover specialty clins; tchg activ also avail. Cyto, biochem & molec lab svcs onsite.
- Dr. Gail Herman, Children's Hospital Research Institute, 700 Children's Drive Rm#W403, Columbus, OH 43205; Fax: 614-722-2716; HermanG@pediatrics.ohio-state.edu. EOE/AA
- PORTLAND OR: Immediate opening for PT Research Associate as Clinical Research Manager & Storage Disease Patient Coordinator. Min 3-5 yrs rsrch exp req. Knowledge of FDA, DHHS & other rsrch-related genetic guidelines a plus. Strong org, i'personal & written skills, trouble shooting skills & budget exp req. Manage clin rsrch trials & coord pt care for lysosomal storage diseases; provide direction for plng, implement, operations & eval of all regulatory & pt care

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- aspects of clin rsrch proj.

  \*\* Ltr of interest outlining past rsrch & pt care trng & exp, genetics background, current CV & names, © & EM for 3 refs: Sylvia Hathaway Oregon Health Sciences University CDRCP, 3181 SW Sam Jackson Park Rd, Portland OR 97201. EOE/AA
- PHILADELPHIA PA: Immediate opening for BC/BE Ped & Genr'l Genetic Counselor. Interest in peds & willingness to assist 3 GCs in coverage of dynamic Genetics division in urban hosp w/ 2 geneticists. Opptys for grant writing to seek add'l funding for future projs. All aspects of ped GC, tchg residents, GC & med students. Coverage of all aspects of Genetics prog req at times.

   Adele Schneider, MD, Developmental Medicine & Genetics, Albert Einstein Medical Center, 5501 Old York Rd, Philadelphia PA 19141;

  ②215-456-8722; Fax: 215-456-2356; schneida@aehn2.einstein.edu. EOE/AA Member of Jefferson Health System.
- PHILADELPHIA PA: See San Diego, Genzyme
- PROVIDENCE RI: Immediate opening for 2 FTE BC/BE Genetic Counselors. Abil to work i'pendently req. Exp pref. Join expanding GC staff at busy PNDx ctr.
- Debbie Owens RNC, MS, Prof Coordinator, Women & Infants Hospital, 79 Plain St, Providence RI 02903; ©401-453-7510; Fax: 401-453-7517. EOE/AA
- Austin TX: See San Diego, Genzyme
- DALLAS TX: See San Diego, Genzyme
- FORT WORTH TX: Immediate opening for BC/BE Genetic Counselor. Motiv, abil to work i'pendently, travel to satellite clins req. Spanish a plus. Join busy, expanding PN prac w/ 5 perinatologists, 1 perinatologist / BC medical geneticist, 4 GCs.
- Practice Manager or GCs: Heather Haymowicz, Yvonne Hulsebos, Dawn Jacob, Melanie Hathaway or Kim McMillen, Obstetrix Medical Group of Texas, P.A., 1325 Pennsylvania Ave Ste 690, Fort Worth TX 76104-2133; 817-878-5298; Fax: 817-878-5289. EOE/AA
- SALT LAKE CITY UT: Immediate opening

- for BC/BE Genetic Counselor. Demonstrated commun skills & abil to work i'pendently, commitmt to exlnt customer svc req. Stat analysis, data collect & grant writing exp pref. Provide rsrch genetic services for I'national Genetics Research & Consultation Prog: direct client GC & prog devel, facil rsrchrs w/ plng & implement of proj, GC for rsrch subjects re: genetic disorders &/or birth defects, provide accurate & up-to-date genetic info to lay & med commun, maintain accurate rsrch records. Work directly w/ PIs in Genetics & Peds Depts.
- University of Utah, 50 N. Medical Dr, Rm 2C412, Salt Lake City UT 84132; ©801-581-8943; Fax: 801-585-7252. EOE/AA
- FAIRFAX VA: Immediate opening for PT (28 hrs/week) BC/BE Genetic Counselor. Join 3 GC & 3MD PN genetics specialists providing c'hensive clin svcs to ob and ART population. Team & independent work atmosphere with opptys for publication. Potential for FT. □ Lee Fallon, MS, Dirrector Genetic Support Services, Genetics & IVF Institute, Fairfax VA 22031; Fax: 703-698-1137; Ifollon@givf.com. EOE/AA.
- ■TACOMA WA: Immediate and future openings for BC/BE Genetic Counselors. ExInt oral & written commun skills, speak Eng lang fluently & meet stringent Dept of Defense background check. GC in med/ repro genetics & BRCA Initiative Prog.
- \*\* Kathleen Benjamin, Madigan Army Medical Center Bldg, 9902 Lincoln St, Tacoma WA 98431; 253-968-4914; kuthleen.benjamin@nw.amedd.army.mil. EOE/AA

### IN CANADA

■ VANCOUVER, BC: Immediate opening for 2
Genetic Counselors. MSc, excellent org skills, abil to work creatively & i'pendently & on team req.
Famil w/ pedigree progs, Microsoft Access & Excel, an asset. Eng lang fluency; French an asset. Join clin research team: rsrch; ethical review process, proj mngmt, fam hx. Deadline 3/31/01.
Submit app online: www.xenongenefics.com or Human Resources, Xenon Genetics, Inc., #501 - 520 West 6th Ave, Vancouver, BC CANADA V5Z 4H5. EOE/AA.